

The Vermont Connection

Volume 35 (Re)creating New Domains: The Future of
Higher Education

Article 6

January 2014

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Recommended Citation

Hammond, Lindsay (2014) "Meeting their Needs: Transition to College with an Autism Spectrum Disorder," *The Vermont Connection*: Vol. 35, Article 6.

Available at: <http://scholarworks.uvm.edu/tvc/vol35/iss1/6>

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Meeting Their Needs: Transitioning to College with an Autism Spectrum Disorder

Lindsay Hammond

It is important to understand the unique challenges that students with an Autism Spectrum Disorder (ASD) face. In the medical sciences, there is a growing body of knowledge regarding an increase in diagnoses of ASDs, but this phenomenon also impacts those of us in education. Student affairs administrators need to examine what is working on campuses as well as what is missing from creating the most successful experience possible for this population. The author will review the definition of ASDs, housing options for students on the spectrum, current practices, the gaps in literature, and the roles of student affairs professionals and faculty relating to the success, retention, and transition of students with ASDs.

Introduction

In 2012, the rate of diagnoses for an ASD was as high as 1 in 88 children (ASD) (Center for Disease Control, 2012). While these young children are not the students currently living and studying on our campuses, it demonstrates the prevalence of these intricate and highly stigmatized diagnoses. The increase in the number of student diagnosed with ASDs can be linked to the growing body of knowledge regarding the autism spectrum. These students are attending post-secondary institutions with varying levels of social and academic differences (Adreon & Durocher, 2007; Center for Disease Control, 2012). Students on the spectrum, however, may have unique difficulties in accessing support services.

The most noticeable differences between those with ASDs and those without fall under the following categories: difficulty with social skills and communication (Adreon & Durocher, 2007), difficulty with detail-focused processing (Happé & Frith, 2006), and difficulty with adaptation to change in daily routines. Along with these differences and difficulties, there are common transitional issues that many students face. These often manifest as difficulties with classes, studying, time management, and organization. Adding these common transitional challenges that all students face to the new experiences of navigating disability services and ac-

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commodations may create stressful obstacles for students with ASDs to overcome.

University Compliance with the Americans with Disabilities Act

Once students leave secondary education and move into higher education, whether at a community college or a four-year institution, students with special needs and ASDs do not automatically receive the same services and accommodations upon matriculation (Adreon & Durocher, 2007). They must file their disability with the appropriate office and at times might need to “prove” their need for support. Shaw et al. (2010) linked much of the issues surrounding the Americans with Disabilities Act (ADA) compliance to a loose interpretation of ADA statutes. This led schools to begin using the law to verify or reject a student’s claim of a disability instead of using the law to ensure that the student did not face discrimination during the application or admission process (Shaw et al., 2010). This inspired the ADA Amendments Act (ADAAA), a broader interpretation of the ADA (Shaw et al., 2010). Because of ADAAA, student services personnel are no longer solely focusing on verifying whether or not a student *has* a disability. They are now working to determine functional impact of the disability.

There are countless websites that describe student rights and responsibilities in terms of disability support. Associated online forums showed a common concern for—and lack of knowledge surrounding—exactly what post-secondary institutions are supposed to do for students with documented disabilities (Office for Civil Rights, 2011). Once these questions are sorted out, however, the problems of accessing resources on campus and succeeding while in school arise.

The need for legal statutes and legislation protecting students with disabilities in higher education is apparent when looking at the growth of this population. The number of students who self-reported disabilities rose from 3% to 9% between 1978 and 1998 (Hall & Belch, 2000). The increase is striking considering that many of these students may be facing an abrupt transition from receiving government-mandated support to needing to advocate for themselves in a new environment. Arky (2012b), in an article about a college student on the autism spectrum, reminds us,

Add to the challenges of independence the withdrawal of the educational supports and services some of these kids have been receiving since they were as young as 2 years old; those supports vanish when they age out of children’s services. They do not grow out of their autism, and they may very likely have other, accompanying problems, including anxiety and ADHD, that may make things that much harder. (para. 8)

Arky (2012a) adds that because the resources are no longer mandated, it puts added stress on a young adult with an ASD to come out and mark himself as different. Once an individual does choose to self-identify as needing additional

resources or accommodations, it is almost completely up to the student to seek out each of the various offices, directors, counselors, and professors to discuss what might work best.

Further, “The report from the National Joint Committee on Learning Disabilities (NJCLD) says that: at the postsecondary level, there is a lack of uniformity in determining whether an individual is eligible as a person with a disability and in identifying needed supplemental services and accommodations for access” (Vickers, 2010, p. 8). This difficulty in identifying services is also caused by “the absence of a common approach to students with Asperger’s [which] has led to widely differing interpretations of what constitutes ‘reasonable accommodations’ for them on campuses, as required by federal law” (Farrell, 2004). This demands an examination of the processes that our universities are using. Despite a legislative right to reasonable accommodations, students still struggle to access, understand, and interpret the services available to them.

What Are Schools Doing?

Most schools offer resources for students with varying learning differences or needs, but others go beyond the typical services offered. “The common experience reported in interviews is that once autism-spectrum students learn to navigate the things that most people take for granted, the better the college experience” (Jones, 2012). Some of these institutions offer specialized programming to students with learning disabilities, including those with Asperger syndrome and others along the Autism Spectrum, which support the successful navigation of life in college. Most of the schools offering specialized programming focus on mentorship and supporting academic and behavioral skills. A few programs focus on the transition to college with attention to the acquisition of independent living skills. Mercyhurst University’s website notes that fewer than twenty colleges offer structured services to help students with ASDs (“Asperger Initiative at Mercyhurst,” 2012), but almost all of these programs charge additional fees of up to thousands of dollars per semester (“Programs for Students with Asperger Syndrome,” 2012).

Taft College offers one of the more unique programs, providing a two-year residential living experience called “Transition to Independent Living” (“TIL,” 2011). This residential program is located within a residence hall designed specifically to fit the unique needs of students with Asperger syndrome and other ASDs. The program is designed for students to learn effective decision-making skills in a college environment and to learn how to take care of their own needs. Typically, students with ASDs who initially live on-campus often relocate to live in close proximity to strong support networks such as family, but the students that graduate from this program often have the skills necessary to live on their own and independently from their families.

Mercyhurst University also hosts a strong program called the Asperger Initiative at Mercyhurst (AIM), which

is designed for students who, while exhibiting superior intellectual ability, face challenges in executive functioning and social interactions... our students participate with faculty and staff in an advisory board to identify what students with ASD require to succeed on this campus. (“Asperger Initiative at Mercyhurst,” 2012, para. 2,3,5)

This unique advisory board calls for faculty, staff, and students to work together to create the most effective and successful environment. Thus, responsibility for student success does not just fall onto the lap of student affairs professionals, but also onto the lap of faculty as well.

Landmark College in Vermont models exemplary resources and implementation strategies because of their unique service they provide to students with learning disabilities. The admissions office markets the school as “The College of Choice for Students Who Learn Differently” (“Landmark Channel,” 2012). In a web video on Landmark College’s website, the students and faculty agree that “there is no one-size fits all” approach and “everything that they can do to help you succeed, they do” (“Landmark Channel,” 2012). This is a school that prides itself on innovative and integrated approaches for students with learning disabilities such as Attention Deficit (and Hyperactive) Disorders, Dyslexia, and ASDs.

The Literature Gap

In the mid-1990s, Morgan (1996) noted that there was a large research focus on children with ASDs and a markedly smaller focus on adults and college-age students on the spectrum. Adreon and Durocher (2007) added that although there has been more research on college-age students with ASDs, there still exists a literature gap regarding their transition from high school to college. Harpur, Lawlor, and Fitzgerald (2004) focus the first twenty pages of their book, *Succeeding in College with Asperger Syndrome*, on the topic of preparing for college. The transitional needs of these students are threaded throughout the book in sections such as “You’re on your own now” and “To see or not to see the support office” (Harpur et al., 2004).

These chapters reference the many commonalities students with learning disabilities share with other marginalized students and the similar challenges that they might face when first entering college. The unique struggles for a student on the autism spectrum, however, encompass a wide range of transitional challenges. These often include setting a routine or plan for each day, (Arky, 2012b), explaining to others the characteristics and challenges associated with ASDs (Willey, 1999), as well as the heightened need for self-advocacy and the “risk of social isolation due to difficulty forming relationships” (Adreon & Durocher, 2007).

In Adreon and Durocher's (2007) work, they addressed the topic of "Adjusting to the Transition" (p. 277), but, like many others, noted problems that all students face: acclimating to campus and being away from home. Research omits how universities can best prepare a residence hall, its residents and staff, academic advisors, staff members, and all faculty to promote success for students with ASDs. Many pamphlets on study habits for students with ASDs do not differ much from suggested study habits for other college students ("Understanding and Identifying Autism," 2004). Other books meant to be used as guides for parents or students often work under the pretense that the student will be actively seeking out guidance when needed, or that the resources on the chosen campus are helpful or accommodating (Harpur et al., 2004; Palmer, 2006; Willey, 1999).

Another problem, still unresolved, is battling the stigma surrounding students with invisible disabilities. A conversation with the mother of a student with learning disabilities and Attention Deficit Hyperactivity Disorder (ADHD) shed light on the student's embarrassment of asking for "extra help" while seeking services (personal communication, November 10, 2012). The sensitive nature of this student is not an anomaly. This stigma is largely ignored when discussing how students with ASDs can access these resources and services. Much information comes from observations and researcher points-of-view, with little information coming directly from students with ASDs. Some books are written or co-written by students with an ASD, but they do not seem to focus much on the primary struggle of talking about one's learning differences and diagnosis of having an ASD. While there is significant research on the presence of stigma surrounding disabilities, the theory-to-practice component to destigmatize them is still largely missing. Thus, we arrive at the problem of how to encourage students with ASDs to utilize resources without marginalizing them. This stigma is a detriment to the possible success and future engagement of students with visible and invisible disabilities.

What is the Role of the Student Affairs Staff?

Among many of the challenges that college students with ASDs face, they "are likely to be quite socially isolated and may experience considerable loneliness" (White, Ollendick, & Bray, 2011). Although many programs and services fight to combat these social issues, student affairs staff members often are tasked with preventing this isolation. Palmer (2006) writes at length addressing the issue of self-disclosure of one's disability and the isolation and feelings that might follow. The body of literature on this subject lead to the conclusion that universities need a proactive, not a reactive, call to student affairs staff to consider the unique situations of these students.

Social justice advocates recognize that students with ASDs fall under the same category as other students from commonly marginalized groups, but face the unique problem of being invisible unless they choose to self-advocate or “out” themselves. Student affairs professionals can act as social justice advocates for students with ASDs and other learning disabilities. This will enable them to bring into the public eye the unique barriers that these students face and will urge faculty to work more directly with staff and students. Mercyhurst University, as mentioned before, has had a successful program for over 30 years because of their adoption of the student, faculty, and staff advisory group to help students with ASDs (“Asperger Initiative at Mercyhurst,” 2012). Student affairs professionals should prepare themselves as best as possible to be advocates for the needs of students with visible and invisible disabilities just as social justice advocates have supported the needs of underrepresented ethnicities, races, and other marginalized identities in higher education. Colleges have been diversifying their campuses and opening their admissions to these underserved groups, but there is still much work to be done to ensure that these students receive the best possible chance for success, education in classes, and experience while in college.

Conclusion

Fortunately more work is being done in this field. The State of Wisconsin Department of Public Instruction has recently published educational literature for students with disabilities that focuses on the transition to life after secondary education. This includes pamphlets on self-determination skills, employment, adult services, and, more pertinent to the field of student affairs, a handbook for *Opening Doors to Postsecondary Education and Training* (Kallio & Owens, 2012). As more of these guidebooks are published, scholars and student affairs professionals can better share, examine, and find the best practices. By following the lead of such institutions as Taft College, Mercyhurst University, and Landmark College, other schools can employ successful intervention and prevention strategies to create an environment conducive to the success, retention, and engagement of students with ASDs and other learning disabilities. Working with a student with learning differences may pose many challenges to student affairs professionals. However, with the services and systems to which these professionals have access, they are in a unique position to impact change. This change starts with bridging the gap for these students, linking the academic world with appropriate and accessible support.

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